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Research Paper

Unequal treatment: health care experiences and needs of patients with cancer from minority ethnic communities

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What is known

- The quality of studies of cancer and palliative care in relation to the health and wellbeing of members of minority ethnic backgrounds is variable.
- There are significant issues and challenges facing members of ethnic minority groups when accessing cancer care services.

What this paper adds

- Evidence of unmet needs among patients with cancer who are members of minority ethnic groups. This evidence includes persistent failure and neglect in terms of cancer care and institutional discrimination which prevent patients from accessing good quality of care and services.
- Evidence of poor communication practices between clinicians.
- Concerns about informed consent and legal right to interpreting or advocacy services.
- Examples of how ethnic and cultural identification give meaning to individual's lives and the positive impact that well-matched advocates can make to patients' knowledge and understanding of various aspects of their illness.

ABSTRACT

This study aimed to explore the health care experiences of members of minority ethnic groups regarding the patients with cancer. A grounded theory approach and semi-structured interviews were conducted with a purposeful sample of 50 respondents who represented the largest minority ethnic groups in a metropolitan UK city. These included 35 patients with cancer from African-Caribbean, Irish, Pakistani, Indian, Bangladeshi and Chinese communities, eight of their carers; and seven community bilingual advocates involved in supporting members of minority ethnic groups who had cancer.

Respondents' experiences of health care were highly variable. Some patients had positive experiences of certain aspects of care, including emotional support from advocates. However, the basic needs of many patients were commonly not met. Effective

access to appropriate care, information and communication was compromised, including at critical times such as when imparting a cancer diagnosis or discussing treatment options. Continuing care was characterised by a lack of service responsiveness and flexibility across care pathways and social services, with patients often unaware of their entitlement to support related to their cancer. The study provided continuing evidence of institutional racism and inequality in patients' experience of health care. Service providers and policy makers should focus on improving elementary quality of care for all as a matter of urgency.

Key Words: Cancer, Ethnic Minorities, Advocacy, Service Provision, Communication

Introduction

In the UK, tackling inequalities in health and health care among disadvantaged and minority ethnic communities features in numerous health policies (see for example, Department of Health 2011a; 2011b; Department of Health 2010; Department

of Health 2009). The latest strategy on improving cancer outcomes advocates a human rights approach to delivering personalised cancer care in which each individual's personal needs, including those rooted in culture and race, are identified through individual assessment (Department of Health 2011a). The strategy states that '*equality issues should not be an add-*

on, but rather should be embedded by all aspects of cancer services in implementing this strategy' (Department of Health 2011a, p69). Such concerns and policy direction have arisen predominantly from epidemiological and cross-sectional research demonstrating differences in mortality or uptake of treatments and services between minority ethnic groups (Bhopal 2013). Health inequality among members of minority ethnic groups is not just a concern in the UK. In the US, the prevalence of major illness such as cardiovascular disease, diabetes, and cancer and associated mortality is rising amongst some minority ethnic groups (Devi, 2008). After controlling for demographic, socioeconomic and lifestyle factors, health care for members of minority ethnic non-white groups, namely African American and Latino, remains of considerably poorer quality than for patients of white ethnicity (Devi, 2008). Elkan *et al.* (2007) highlighted the surprising lack of qualitative research to illuminate why such inequalities may arise, at what point in care pathways they are most likely to occur, and their effects on patients' experience. In 2015 there is still a lack of qualitative research about these issues.

Historically, the focus of reducing ethnic health inequalities in the UK has been on heart disease, mental illness and diabetes, rather than cancer (Randhawa and Owens 2004). Little seems to have changed in terms of addressing a policy focus that is particular to cancer in ethnic minority groups. The current *NHS Outcomes Framework* (Department of Health 2013) includes cancer as one of the principle areas for improvement, but, like the *Health and Social Act 2012*, the focus is on reducing 'health inequalities between the people of England' (p6) rather than on minority ethnic status or social disadvantage. In the indicator 'preventing people from dying prematurely', the ethnicity data for those 'under 75 mortality from cancer' is indicated as 'not currently available but possible to construct' (pg16). This is clear evidence of lack of focus, priority and urgency.

In a study examining cancer incidence in South Asian migrants to England in the period 1986-2004 (Maringe *et al.* 2013 p1891) found that 'both ethnicity and social deprivation exerted separate effects on cancer incidence, with the nature of the deprivation gradient being to a large extent ethnic specific'. The study reported that cancer incidence is rising in South Asians.

There is evidence that there is a higher incidence rates of certain cancers in ethnic minority groups compared to the White ethnic group (National Cancer Intelligence Network 2013). The first national report on cancer incidence by ethnicity for multiple cancer sites published in 2009 found that even though ethnicity data was not complete, 'people from the Black ethnic groups have higher rates of myeloma and stomach cancer and males from the Black ethnic group have higher rates of prostate cancer. Liver cancer is higher amongst people from the Asian ethnic group compared to the White ethnic group, as is mouth cancer in females and cervical cancer in the over 65s' (National Cancer Intelligence Network 2013, p11).

A review literature reporting the views and experiences of members of minority ethnic groups regarding cancer care reported poor understanding, among providers, of their needs and a lack of education and awareness of support services among communities. Low socioeconomic status among people of Pakistani and Bangladeshi origin, poor grasp of English,

neglect of religion and culture in treatment and palliative care services also emerged as other important factors. The lack of qualitative examination of the care experiences of members of minority ethnic groups living with cancer themselves was highlighted. The lack of attention paid to minority ethnic groups was also criticised (Elkan *et al.* 2007). Redman *et al.* (2008) reviewed all the literature in relation to ethnicity, cancer and palliative care in the United Kingdom. They concluded that 'there appears to be a strong need for research strategies that focus on service users' perspectives' (Redman *et al.* 2008, pg. 148). Results from a recent English Cancer Patient Experience Survey (Saunders *et al.* 2015) show that patients who are members of minority ethnic groups report more negative experiences than White ethnic groups. A more targeted study exploring the lived experience of breast cancer, diagnosis and treatment amongst Gujarati speaking women (Patel-Kerai *et al.* 2015) highlight the importance of a qualitative approach based on phenomenological epistemology in capturing lived experience from a cultural perspective. The study reported in this paper aimed to explore experiences of, and needs for, cancer care among members of a range of minority ethnic groups in order to inform practice and reduce health care disparities.

Methods

Ethics

Ethical approval was obtained from South Birmingham Research Ethics Committee. To ensure maximum comfort and to reduce distress, the participants were made fully aware that the interviews were to be carried out at their own pace, they could stop at any time during the interview and were not obliged to continue if they became distressed or if they did not wish to continue. Time was given to patients who wished to stop and restart the interviews.

Research design

We used a non-experimental qualitative design to focus upon the perceptions and experiences of those receiving an advocacy cancer service, their carers and cancer care advocates in relation to patient care.

Sampling

We used purposeful sampling (Silverman 2001) to capture a range of patient experiences, backgrounds and care contexts in a metropolitan UK city in which over a third of the population were recorded as belonging to a non-white minority ethnic group (2011 Census: Key Statistics for Birmingham and its constituent areas). Participants were recruited via a patient advocacy service which supported members of minority ethnic groups who had a cancer diagnosis. This service was aimed at six of the largest minority groups in the city, of these 5 were from non-white groups with the Irish group being classed as the white group. The service received referrals from health professionals who identified individual patients who might benefit from the service and through self-referral. Written invitations, translated where appropriate, were sent, by the advocacy service, to all patients with whom the service had had some form of contact; all those invited to participate had been in contact with the service during a specified six month period. Those who did not respond and

had not declined to be contacted by the service were followed up by telephone or at home to discuss participation and provided with further information about the study. Written informed consent was subsequently obtained from all participants prior to interview by the interviewer.

Data collection

Face-to-face semi-structured qualitative interviews were undertaken by QF, an experienced bilingual qualitative female researcher who spoke English, Mirpuri and Urdu/Punjabi, the main languages of the participants. These required considerable sensitivity with seriously ill individuals and families living with cancer and protection of participants' confidentiality. The interview schedule was developed to capture a range of experiences of cancer and cancer care. The schedule covered participants' personal, social and health circumstances prior to receiving a diagnosis of cancer and prior to receiving help from the advocacy service, their experiences of receiving a diagnosis and their experiences of hospital visits and care, their personal, social, financial and health circumstances, their current needs and their experiences of the advocacy service. Topic prompts were added; these were derived from the pilot interviews. Interviews lasted between one and a half to three hours. Interviews were conducted in participants' own homes and audiotaped; if recording was not acceptable, were recorded in writing with the participants' permission. All taped interviews were transcribed verbatim in English, following their translation by QF where appropriate. Written records of interviews and tape transcriptions were further read and checked for accuracy by the main field researcher (QF).

Participants were given the option of being interviewed in English or in their mother tongue. The Bangladeshi, Irish and Chinese speaking respondents spoke fluent English and wished to be interviewed in English. The Pushtu speaking respondent was fluent in Urdu and was interviewed in Urdu. It was not possible to match gender/ethnicity of all those being interviewed with the interviewee within the limitations of the study but, in terms of language, the participants felt comfortable with was provided.

Data analysis

Data were collected and analysed concurrently enabling emergent themes to be explored and tested in subsequent interviews (Strauss & Corbin 1990). Coding was developed and agreed by discussion between the two lead researchers (QF, a social scientist and JK, a primary care clinical academic) as analysis proceeded, alongside examination for deviant cases, until no new themes or categories emerged suggesting saturation (Strauss & Corbin 1990). Participant validation was not undertaken to avoid a potential burden or distress in re-approaching individuals who might have died or become more severely ill. Instead the feedback and validation process involved a focus group with 6 advocates to generate themes which were then further explored in individual interviews with seven advocates, six of whom had also participated in the focus group interview. The advocates included five women and two men; they were drawn from African-Caribbean, Irish, Muslim Urdu/Punjabi speaking, Indian Punjabi, Gujarati, Hindi speaking, and Pakistani Mirpuri speaking backgrounds. Findings were, with

Table 1. Summary of range of clients' needs.

Clients care need	Number of clients who expressed a particular need	% of clients who expressed a particular need
Health Information	18	14.4%
Accessing Welfare Benefits	6	4.8%
Practical needs	9	7.2%
Communication with service providers	13	10.4%
Daily social care needs	4	3.2%
Dealing with service providers	5	4%
Emotional support	20	16%
Housing	3	2.4%
Childcare	1	0.8%
Mental Health	1	0.8%

respondents' permission at interview, fed back and discussed in the focus group and individual interviews with those advocates supporting members of minority ethnic groups in cancer care. This helped to confirm and refine the analysis.

Data were analysed using thematic analysis. 'Needs' emerged as the overarching theme. We refer to 'care need' as a person's ability to benefit from care such as input from a statutory or other service (Culyer 1976). Arguably, needs are worth assessing when something useful can be done about them. Thus by 'needs assessment' we mean the identification or provision of useful information for those involved in prioritising, developing and delivering services. There was wide ranging evidence of patient care needs, met and unmet, across participants' accounts. Table 1 summarises the range of needs identified. Findings are presented in relation to participants' experiences of their cancer care needs and of delivery of services in relation to these needs.

Findings

Study sample and context

The sample consisted of 35 people with cancer and eight carers. The sample was representative of the advocacy service clientele and the city, as was their range of cancer diagnoses, though not the UK as a whole. However, it is acknowledged that this sample was drawn from clients of an advocacy service and was therefore likely to present a particular range of needs.

Fewer carers were recruited as the researchers envisaged that most people with cancer either did not have a carer or were reluctant for their carers to be interviewed because of constraints on their time. All the carers interviewed were relatives: daughters, daughters-in-law, one partner, and one mother (Table 2). Most of those with cancer were receiving hospital specialist review or treatment in one of five hospital Trust unit settings; three were in a palliative phase of care in one of three hospices. More than two thirds were not in employment and on low incomes in receipt of welfare benefits. Most had not been in paid employment prior to their illness.

Emotional Support Needs

Emotional support was an ongoing need. Advocates provided support in a variety of different ways which were culturally

Table 2: Patient characteristics.

Self- defined ethnicity	Patient respondents	First language	Gender
Pakistani	12	8 Mirpuri, 3 Punjabi, 1 Pushtu (also fluent in Urdu)	8 women 4 men
African Caribbean	8	8 English	7 women 1 man
Indian	8	7 Punjabi 1 Gujarati	6 women 2 men
Irish	5	5 English	5 men
Bangladeshi	1	Bengali (also fluent in English)	1 woman
Chinese	1	Chinese (also fluent in English)	1 woman
Total	35		

relevant and acceptable for a particular individual. One African Caribbean advocate prayed with African Caribbean clients in their times of distress and participants reported that they found this to be a great support. For one participant, who was from abroad, isolated and living in a hostel, the advocate invited her to church and she reported the importance of this to her.

'it does really help me a lot. She even go out of her way and invite me to church and her brother sometimes will pick me up and bring me to the church that she attends..... and they pray for So she really does help me in a good way and that's good because normally some people who are working and they are Christian they don't want to, like involve their Christian life in their work'. (Participant 9, African Caribbean female aged 68)

Another African Caribbean woman (Participant no 32, aged 68) reported that her advocate was 'more of a friend'. She said that she looked upon her advocate as a 'mixture of a friend, adviser and a counsellor'.

Indian Punjabi speaking female participants also reported that their advocates provided them with emotional support as well as befriending and that it was important for them to have someone to talk to outside the family. For example:

'She supported me, she would meet me at the hospital and sit with me when I needed company and talk to me'. (Participant 3, Indian Punjabi, female, aged 53)

'she listens she is good, if there are times when I want to just talk to her, she listens'. (Participant 20, Indian Punjabi, female, aged 56).

The Irish advocate found himself dealing with very complex emotional issues related to the historical background of Irish men. He spent time talking, reminiscing and helping them to talk openly about their feelings about the past and the future.

There were two cases where emotional needs were not being met. These were due to the inappropriate matches between clients and advocates. Both clients were Pakistani females and

they had been matched with a Pakistani male advocate, when they preferred a female. This was rectified when it was brought to the attention of the service.

Communication Needs

i) *Experience of liaising with health professionals and services*

Participants with limited or no fluency in English (n=16) underlined their need for the facilitation of communication and language in service encounters as this affected their ability to access information about their illness and care options. All reported a need for someone to communicate on their behalf with the English speaking world in health and other service contexts, particularly in secondary care and non-general practice settings in the community, such as nursing. Most of these respondents were registered with a general practitioner who shared, or partially shared their mother tongue, which facilitated their communication in this setting.

ii) *Compromised experience of interpretation*

Thirteen non-English speaking participants routinely used their family or relied on the goodwill of friends to interpret for them in hospital. If they were not available, participants had to go do their best to communicate. They reported that the provision or use of interpreters was not regular practice in the hospitals they attended. Consultations occurred with no interpretation at all or with health professionals asking other members of staff such as junior nurses to interpret. Some participants did not ask for trained interpreters because they were uncertain of any entitlement or because they feared it would be seen as bothersome. For example:

'I did sort of know (about access to an interpreter). Sometimes you can be scared to ask just in case someone takes offence, and you don't want to trouble them'. (Participant 14, Pakistani Punjabi, female, aged 45)

Other participants asked their advocates to go along with them and interpret. Interpreting within the advocacy service was not a clearly defined role; some advocates interpreted whilst others did not. All the advocates felt that many health care service providers assumed that their only function was to interpret and that this perception undermined the totality of their role.

iii) *Common consequences of unmet communication needs*

Communicating through family and friends was reported to have contributed to both relationship and communication problems. For example, there were instances of informal interpreters withholding information. As an example, one woman (Participant no. 31: Pakistani Mirpuri speaking female aged 66) reported that her son had kept from her that she had cancer and the probability of surviving the cancer until she had been told that things were 'clear'. Her son developed mental health problems which she felt were the result of him being burdened by not disclosing this information to her. Another woman of Pakistani background, who lived on her own, reported that she had to take a number of different people each time she went to hospital. She explained the difficulties that she faced in getting them to give her an accurate interpretation of what was being said:

'When I went to get the results and this was the time when I took this person and she couldn't understand and I tried to understand and listen with the little I could speak. I then realised I needed to take someone who can speak English. When I went the second time and took another person the doctor explained to her and she hid it from me, she was afraid that I would get upset. She said don't worry this is nothing. And I went quiet. Then when I went with her the second time and the same happened I said to her tell me on your son's life. Tell me the truth I need to know. Don't worry I need to know what the truth is. She then told me exactly what the doctors told her. This last time yesterday, I took a person who was very good she is a doctor's wife and she told me word for word and stopped them as she explained to me'. (Participant 14, Pakistani, Punjabi, female, aged 45)

She was not offered interpreting by hospital services nor did she feel her advocate had helped her to access or secure interpreting services. A Pakistani male client, who has since died, had no family available to assist him with interpretation and struggled:

Interviewer: 'When you go to the hospital who explains things to you'?

Client: 'I go alone, when I go there sometimes there is a nurse who speaks Urdu, she translates for me and I understand some things and other I do not understand'.

Interviewer: 'What do you do about the things that you do not understand'?

Client: 'Nothing I just go silent'.

Interviewer: Do you question more to understand?

Client: 'No'.

Interviewer: 'In the hospital the last time ... who translated for you'?

Client: 'No I explained myself. There were two white doctors....'

Interviewer: 'How did you explain'?

Client: 'I just explained using signs'.

Interviewer: 'How'?

Client: 'I said "my shoulder pain" (said the words "my shoulder pain" in English and points to the shoulder).

(Participant 2, Pakistani, Mirpuri, male, aged 48)

He communicated using the little English he possessed and signing. He had been told he had lung cancer. However it emerged at interview that neither he nor his wife knew what 'lung' meant in their first language and thus they were unaware where in the body the cancer was.

In another case a lack of communication almost resulted in a woman being diagnosed with dementia. A carer of a client related how, during a visit to hospital, her mother-in-law became very confused and the doctors became concerned that she might be showing signs of dementia. Her son tried to explain to them that this was not the case. However, he found that he had problems getting the consultants to understand and he then rang the advocate and asked the advocate to intervene. The advocate helped the family explain that his mother was confused due to the unfamiliar environment and was not

showing early signs of dementia (Participant. 33, Pakistani, Mirpuri, female aged 30).

The Need for Health Information

i) Patients' understanding of their cancer/Information about illness

There were many examples of African Caribbean women, Punjabi speaking Indian women and Irish men actively seeking information regarding their illness through their advocate. This shows that interpreting was not the only issue, that individuals needed advocates, even if they could speak English, to help them to gain a better understanding of the process of treatment, medication and other issues such as reconstruction after mastectomy.

One Irish man (Participant no 18, aged 75) had made a choice not to have treatment and he reported that all the processes and consequences of his decision had been explained to him fully. His Irish welfare adviser felt that he had made a well informed choice. Another Irish couple reported asking questions about the illness and finding it very useful to have a well informed Irish advocate.

'When he (husband) was having his radiotherapy we didn't know what it involved and he (advocate) came here with a book and read all the things out to us that we needed to know. Told us what it involved and everything and just sort of said it to us. My husband said is it going to do me any good? And he said they wouldn't be doing it if they didn't think it would, because it's expensive. So yes, he helped us in all sorts of ways.' (Participant 35, Irish, English, aged 54)

In contrast participants from Pakistani backgrounds, particularly those who were non-English speaking, often appeared to have major needs to understand their illness and its treatment. They tended to pose questions to the researcher thus, for example:

'I've had my glands taken out. You know my arm is always tired and that. Do you know if this will carry on?' (Participant 13, Pakistani, Punjabi, female, aged 35)

'.... do people with breast cancer get better?' (Participant 14, Pakistani, Mirpuri, female, aged 42)

'Do you know what it (lung cancer) is?' (Participant 2, Pakistani, Mirpuri, male, aged 48)

When asked if she felt she knew about her illness, participant 5, a Pakistani woman aged 58, she said that she hadn't been told anything about it or the prognosis. The doctors had not told her if she would get better or how long her treatment would take. She had not asked them. She had been having chemotherapy for six months and was on medication which was explained to her by her daughter-in-law. When asked what she knew about chemotherapy, she said that, 'the body is like a plant with cancer as the disease and chemotherapy is like giving plants the water they need to survive'.

Access to welfare benefits

Many participants were receiving welfare benefits to which they were entitled and which were facilitated by hospital staff when

diagnosed. However, one Pakistani, Mirpuri speaking female aged 55 (Participant no 6) also reported the extra expense involved in having cancer, she reported that she had to visit hospital 17 times in over a month and this was extremely costly, she was on state benefits and she was not aware of any claims she could make for travel expenses. Six other clients, five of whom were non-English speaking, were experiencing lengthy delays in the processing of benefit claims or were not aware of benefits such as the carers' allowance and attendance allowance to which they appeared entitled. For example, one Pakistani woman with a terminal illness phase had not claimed the attendance allowance to which she was automatically entitled (Participant no. 6: Pakistani, Mirpuri Speaking female aged 68). An Indian Sikh man lost four months of benefits. He reported that the hospital social worker had not informed about these benefits then and it was only when he came into contact with the advocacy Service that he realised his entitlement Participant no. 22: Indian, Sikh, Punjabi speaking male aged 70).

Advocates confirmed how people with cancer and their families experienced various impediments:

'One (of my clients) has missed out on a year's worth of benefits... The families don't understand what is going on, they're trying to cope with the diagnosis and six months later they've got no money coming in... Then they have to think whether they want to go for an appeal which means filling out more forms ...its just another stress involved'. (Advocate A).

'I don't understand why anybody should be leaving hospital (after) three or four months and not be told about it (benefits), they're not helped with the forms and when they do, ...one occasion with my client's family they were told that you know they should be looking after their own... That person's lost out on nearly six months-worth of benefit. They have struggled and struggled' (Advocate B).

Advocates varied in their approach. Most did not see completing application forms on behalf of clients as part of their role by most which was to signpost them to neighbourhood or benefits offices. Although advocates felt unqualified to offer advice, some appeared to explore benefit issues with their clients. They would complete application forms recognising clients' difficulties or would find out whether clients were entitled.

Practical support needs

Advocates appeared consistently helpful in supporting people with a range of practical needs. They facilitated successful applications grants for items such as washing machines, beds, occupational therapy equipment such as rails and steps as well as larger more expensive items such as repositioning a bathroom and toilet. For example, a Muslim male advocate facilitated a Pakistani male client's successful application to Social Services for a downstairs bathroom to be built on to the back of the property.

When families attempted to apply for such items without an advocate's input they reported difficulties. For example, one Pakistani man's carer reported their difficulties in getting Social Services to send them an application form for a bathroom grant (see quote below).

'When (advocate) came in and he says you can get the form yourself, he gave us detailed way of where you get them from and obviously when my husband went they wouldn't give it to him. Saying that we don't do that, we can't do that. And then when (advocate) rang them up and explained everything then they sent us the application form. Then they wouldn't help with filling it. So its like stumbling blocks, they keep pulling out in front of you.'

(Participant 34, Pakistani Mirpuri, aged 33)

Continuity of Care

In a number of cases there was a complete lack of continuity of care. One woman who was at the later stages of stomach/bowel cancer, found that every 4 weeks she had a build up of ascites and had to go into hospital to have it drained. Every time she had to go into hospital she was told to go in through the Accident and Emergency Admissions process. The family found this extremely distressing and raised this with the consultant who had told them that this was the process. In another case a man was discharged from hospital without appropriate post-operative care. A Sikh Punjabi-speaking man, was eventually diagnosed with a brain tumour after much confusion regarding his symptoms and going back and forth to hospital (Participant 10, Indian Punjabi Male aged 55). Once diagnosed, he underwent surgery. When he was discharged from hospital, no district nurse or social care input was arranged until his Punjabi-speaking female advocate arranged for regular nursing visits, the provision of essential equipment at home and for a social worker to undertake a social care needs assessment.

Discussion

This research aimed to explore the experiences and needs people with cancer and who were also members of minority ethnic groups. The findings from the study are largely consistent with previous literature demonstrating an overall poor quality of health care (Devi, 2008). The results also seem to offer considerable support for the conclusions drawn from the systematic review by Elkan *et al.* (2007) and from a study by Worth *et al.* (2009) which examined access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland. The Cancer Patient Experience Survey 2011/12 (Department of Health 2012) highlighted that members of minority ethnic groups tend to be less satisfied with all aspects of services particularly with regard to understandable communication, sufficient care after discharge and staff working well together.

Even though our study is concerned with the experiences of members of minority ethnic groups, other populations are also likely to experience unmet emotional and information need in cancer services. The Cancer Patient Experience Survey 2012/2013/2014 National Reports, (Department of Health 2012; Quality Health 2013; 2014) has found a mixed bag of experiences that depend on a number of factors that resulted in positive experiences such as; patient case mix (Abel *et al.* 2014), location, with poorer experience in London than elsewhere (Saunders *et al.* 2014), whether trusts had more specialist nurses (Griffiths *et al.* 2013) and the kind of cancer being treated as general factors that are in play across all patient populations.

One of the key themes emerging from this study concerned appropriate communication, particularly in relation to the provision of interpreting services. More often than not, participants did not receive even basic standards of care during consultations with physicians and other health care providers. Clinicians were particularly careless in their willingness to proceed with consultations in the absence of appropriate interpreting services, despite clear evidence that patients had a very poor and often virtually non-existent grasp of English. Vulnerable people were consistently placed in increasingly stressful, and potentially avoidable situations resulting from an extremely poor knowledge and limited understanding of their own illnesses. This also gives rise to the question of genuine informed consent. There was also an obvious lack of planning and management of long-term care. It is extremely worrying that even basic care and support was neglected by services, and is ultimately creating undue distress in patients and their families. Further efforts should, therefore, be taken to ensure that communication are met adequately, particularly given the severity of a cancer diagnosis.

The availability and uptake of interpreting services were reported as a serious issue. It became more and more apparent that participants did not receive an appropriate level of information about their illness, which is a finding that may undoubtedly be experienced across many health care services and disease states but is often not reported. Clinicians opted for no interpretation or allowed staff or family members, without appropriate bilingual qualifications to interpret during consultations. The pattern emerging from the findings suggested that allowing family members to serve as interpreters resulted in the withholding of negative information from patients to 'protect' them from the psychological impact of their illness. Many participants wished to have specific knowledge about their illness and often found it extremely difficult to discover the details that they required. Lack of information can have a substantially negative impact on both the individual and their family members and carers.

Another key finding that emerged from this study was the positive contribution made by advocacy workers to participants' wellbeing. Advocacy workers provided various levels of support and culturally appropriate services. They also seemed to serve as a key resource through which participants could find out about their illness and treatment processes. It is essential, however, for advocates and clients to be appropriately matched and for advocates to have specific cultural awareness; poor matching may serve as a further obstacle.

In addition, it was obvious that advocates were particularly helpful in raising awareness of welfare benefits and funding for practical matters such as equipment or modification participants' homes. However, there was a need to clarify the role of the advocacy worker. While advocates agreed that their responsibility was to inform patients of their rights in terms of benefits and to ensure the receipt of the appropriate forms, most would not assist in completion of these forms, despite clients hoping and often expecting this to be the case. Similarly, many health care providers imagined the role of the advocate was to act as interpreter but advocates themselves clearly felt that it was not their responsibility even though they were often forced to take on this work. Clear definition of advocacy roles

will, hopefully, raise awareness of other services such as for interpreting and form completion.

It was increasingly apparent that patients from Pakistani backgrounds seemed to have the most unmet needs in terms of communication, access to services, knowledge and understanding of illness and advocacy support. Again, however, more Pakistani advocacy workers could be matched to Pakistani patients in an attempt to improve support to this particular client group. Pakistani patients' advocacy needs seem to be tied in with their communication needs and therefore the facilitation of communication for this group is essential to meet their needs.

Ethnic and cultural identifications added real meaning to individuals' lives and recognition of individual identities by advocates facilitated support. Examples of this could be seen in the Irish men who, at the end of their lives, were helped to come to terms with their historical past and future and the African Caribbean woman who found that going to church and praying helped her with her illness. It is important to recognise and explore the importance of these meanings in people's lives. The importance of racial/ethnic differences and its reflections on cultural competency has been highlighted in a recent study (Charlot *et al.* (2015). Their findings support the benefit of patient-navigator (which is similar to advocacy) race and language concordance on health care delivery in minority women.

Limitations

We recognise that this is a sample of patients taken from a cancer advocacy service and therefore participants would already have been identified as having unmet needs. These are experiences of a small sample of members of minority ethnic groups in city, although their experiences covered a range of hospitals. All the interviews were carried out by one experienced female researcher and therefore cultural sensitivity for each individual's culture in interviewing was not feasible.

Conclusion

This study demonstrates gaps in the care of people with cancer who are also members of minority ethnic groups. These gaps are brought into focus by participants themselves and reveal poor quality care. The findings are particularly distressing given their impact on the physical and psychological well-being of those already experiencing a serious illness and often with a poor overall prognosis. The approach of services needs to be modified promptly to put a stop to their persistent failing and neglect in terms of cancer care for members of minority ethnic groups. There is clear evidence of institutional discrimination as one of the biggest barriers to accessing good quality of care and services. Services seem to be lacking the will to address the obvious needs of their patients resulting in patients from minority ethnic groups not receiving the type of care that they should receive when suffering from cancer.

While the experiences of people with cancer in this study provoke major concerns about quality of care, it is recognised that health providers face significant challenges. These include health professionals' common uncertainty and apprehension in responding to the needs of patients of differing ethnicities

to their own and how this can create a disabling hesitancy and inertia in their clinical practice (Daniels and Swartz, 2007; Kai *et al.* 2007).

Other work has highlighted how cross-cultural communication and thus quality of cancer care may be compromised when third parties are interpreting for patients (Kai *et al.* BJC, 2011). In particular, family involvement in mediation of communication and decision making for patients is particularly challenging (Kai *et al.* BJC, 2011). Health professionals require much better support and practical guidance to work effectively both with trained interpreters and with the common reality of patients' families interpreting for patients. Recent initiatives such as The NHS Five Year Forward View (NHS England 2014), NHS Five Forward View: Time to Deliver (NHS England 2015) and National Cancer Survivorship Initiative Vision (Department of Health, Macmillan Cancer Support and NHS Improvement 2010) to improve quality of cancer care in the UK may present opportunities. These initiatives should include relevant health professional training on how to work effectively with interpreters and advocates and in relation to cancer and ethnic diversity. Interactive resources are available as one step to support service development in these ways (Kai 2005, Kai 2006).

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Conflicts of Interest

None

REFERENCES

- Abel GA, Saunders, CL, Lyratzopoulos G (2014) Cancer patient experience, hospital performance and case mix: evidence from England. *Future Oncology* 10 (9) 1589-1598.
- Bhopal RS (2013) Ethnicity, Race, and Health in Multicultural Societies (2nd Edition). Oxford, Oxford University Press.
- Census (2011) Available at http://www.birmingham.gov.uk/cs/Satellite?blobcol=urldata&blobheader=application%2Fpdf&blobheadername1=Content-Disposition&blobkey=id&blobtable=MungoBlobs&blobwhere=1223529055255&ssbinary=true&blobheadervalue1=attachment%3B+filename%3D86290web_KS201_Ethnic_group_.pdf (accessed 11/09/2015)
- Charlot M, Santana MC, Chen CA, Bak S, Heeren TC, Battaglia TA, Egan AP, Kalish R, Freund KM (2015) Impact of patient and navigator race and language concordance on care after cancer screening abnormalities. *Cancer*, 121(9):1477-83.
- Culyer AJ (1976) Need and the National Health Service. Oxford, Martin Robertson.
- Daniels K, Swartz L. (2007) Understanding health care workers' anxieties in a diversifying world. *PLoS Medicine*, 4 (11): e319. Doi:10.1371/journal.pmed.0040319.
- Department of Health (2010) Equity and excellence: Liberating the NHS. London. The Stationary Office Limited.
- Department of Health (2011a) Improving outcomes: A strategy for Cancer. Department of Health. London. The Stationary Office Limited.
- Department of Health (2011b) Improving Outcomes: A Strategy for Cancer; Assessment of the impact on Equalities. England, Department of Health,.
- Department of Health (2009) *Government's Response to the Health Select Committee Report on Health Inequalities*. London. The Stationary Office.
- Department of Health (2012) Cancer Patient Experience Survey 2011/12. Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212860/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf. (Accessed 11/09/2015)
- Department of Health, Macmillan Cancer Support and NHS Improvement (2010) National Cancer Survivorship Initiative Vision. England, Department of Health.
- Department of Health (2013) The NHS Outcomes Framework 2014/14. London HMSO.
- Devi S (2008) US healthcare still failing ethnic minorities. *Lancet* 371: 1903-1904.
- Elkan R, Avis M, Cox K, Wilson E, Patel S, Miller S, Deepak N, Edwards C, Staniszewska S, Kai J (2007) The reported views and experiences of cancer service users from minority ethnic groups: a critical review of the literature. *European Journal of Cancer Care* 16 (2): 109-121.
- Griffiths P, Simon M, Richardson A, Corner J (2013) Is a large specialist nurse workforce in cancer care associated with better patient experience? Cross-sectional Study. *Journal of Health Services and Research Policy* 18 (Suppl.1) 39-46.
- Health and Social Care Act (2012) Available at: <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted> (Accessed 11/09/2015)
- Kai J (Ed) (2005) PROCEED: *Professionals responding to cancer and ethnic diversity. A training resource and DVD*. London: Cancer Research UK.
- Kai J, Briddon D, Beavan J (2006) Working with interpreters and advocates. In *Valuing Diversity: a resource for health professional training to respond to cultural diversity*, Kai J (Ed), 2nd edition, pp 201-224. London: Royal College of General Practitioners
- Kai J, Beavan J, Faull C, Dodson L, Gill P, Beighton A. (2007) Professional uncertainty and disempowerment responding to ethnic diversity in health care: qualitative study. *PLoS Medicine*, 4(11):e323.
- Kai J, Beavan J, Faull C. (2011) Challenges of mediated communication, disclosure and patient autonomy in cross-cultural cancer care. *British Journal of Cancer*, 105: 918-924.
- Maringe C, Mantani P, Rachet B, Leon DA, Coleman, Santos Silva I (2013) Cancer incidence in South Asian

- migrants to England, 1986-2004: Unravelling ethnic from socioeconomic differentials. *International Journal of Cancer*, 132: 1886-1894.
- National Cancer Intelligence Network (2013) National Cancer Equalities Initiative. Cancer and Equality: Key Metrics. Available at <http://www.ncin.org.uk/view?rid=2243>. (Accessed 08/09/2015).
- NHS England (2014) The NHS Five Year Forward View. England. NHS England.
- NHS England (2015) The NHS Five Year Forward View: Time to Deliver. England. NHS England.
- Patel-Kerai G, Harcourt D, Rumsey N, Naqvi H (2015) Exploring the lived experience of breast cancer diagnosis and treatment amongst Gujarati speaking Indian Women. *Diversity and Equality in Health and Care*, 12 (1): 9-17.
- Quality Health (2013) National Cancer Patient Experience Survey 2014 National Report, England. NHS England . Available at: <https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patient-experience-survey-programme-national-report/file> (Accessed 11/09/2015)
- Quality Health (2014) *National Cancer Patient Experience Survey 2014 National Report*, England. NHS England. Available at: <https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey/2014-national-cancer-patient-experience-survey-national-reports/688-2013-national-cancer-patient-experience-survey-national-report-pdf/file> (Accessed 08/09/2015)
- Randhawa G, Owens A (2004) The meanings of cancer and perceptions of cancer services among South Asians in Luton, UK. *British Journal of Cancer* 91; 62 – 68.
- Redman, J. (2008) Critical review of literature on ethnicity and health in relation to cancer and palliative care in the United Kingdom. *Diversity in health and social care*. 5: 2 p.137.
- Saunders CL, Abel GA, Lyratzopoulos G (2014) What explains worse patient experience in London? Evidence from secondary analysis of the Cancer Patient Experience Survey. *BMJ Open*; 4:e004039.doi10.1136/bmjopen-2013-004039.
- Saunders CL, Abel GA, Lyratzopoulos G (2015) Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site: evidence from respondents to the English Cancer Patient Experience Survey. *European Journal of Cancer Care*. 24, 85-98.
- Strauss A and Corbin, J (1990) *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA Sage Publications, Inc.
- Silverman, D (2001) *Qualitative Research*. Sage Publications Ltd.
- Worth A, Irshad T, Bhopal R, *et al.* (2009) Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. *British Medical Journal*: 338:b183

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